



Testimony Submitted by:

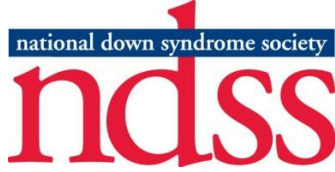
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**Wednesday, May 12, 2010**  
**2:00 PM - 4:30 PM**  
**Rayburn House Office Building 2358-C**

Submitted May 12, 2010 to the United States House Committee  
on Appropriations Subcommittee on Labor, Health &  
Human Services, Education, and Related Agencies  
The Honorable Obey, Chairman

**Summary of Testimony:**

Ms. Will will offer testimony regarding appropriation requests for Down syndrome in Fiscal Year (FY) 2011, specifically the need to implement P.L. 110-374, the *Prenatal and Postnatal Diagnosed Conditions Awareness Act*, at the Centers for Disease Control and Prevention (CDC). The National Down Syndrome Society (NDSS) requests \$5,000,000 for the CDC to support its efforts to implement the law.



Mr. Chairman and Members of the Subcommittee:

As Vice President of the National Down Syndrome Society (NDSS), I want to take this opportunity to thank you for the leadership role this Subcommittee has played over the years in supporting and creating awareness on Down syndrome. I am pleased to offer the following testimony regarding appropriation requests for Down syndrome in Fiscal Year (FY) 2011.

There are more than 400,000 people living with Down syndrome in the U.S., and about 5,000 babies, or one in 733, that are born each year. Down syndrome occurs in people of all races and economic levels, and it is the most frequently occurring chromosomal condition. The incidence of births of children with Down syndrome increases with the age of the mother. But due to higher fertility rates in younger women, 80 percent of children with Down syndrome are born to women under 35 years of age.

Advancements in the treatment of health problems have allowed people with Down syndrome to enjoy fuller and more active lives, and become more integrated into the economic and social structures of our communities. Unfortunately, while progress has also been made in public policies that enhance the lives of individuals with Down syndrome, barriers still exist, making it difficult for people to access adequate health care, housing, employment and education.

We have been working with Congress for decades to address these challenges and advance public policies that promote the acceptance and inclusion of individuals with Down syndrome and other genetic disorders, and help them to achieve their full potential in all aspects of their lives.

Mr. Chairman, we understand the challenges the Subcommittee faces in prioritizing requests, we believe that funding the requirements of the Prenatally and Postnatally Diagnosed Conditions Awareness Act of 2007 (Public Law 110-374) is imperative given the significant impact Down syndrome has on families and communities across the country and the great potential for improvements in quality of life for them and others with chromosomal disorders. On behalf of the National Down Syndrome Society, we recommend that you appropriate ***\$5 million in the FY 2011 to the Centers for Disease Control & Prevention (CDC) to implement the requirements of the Prenatally and Postnatally Diagnosed Conditions Awareness Act of 2007.***

As you know, Congress passed the *Prenatally and Postnatally Diagnosed Conditions Awareness Act of 2007* in October of 2008. This new law seeks to ensure that pregnant women receiving a positive prenatal or postnatal diagnosis of Down syndrome will receive up-to-date, scientific information about life expectancy, clinical course, intellectual and functional development, and prenatal and postnatal treatment options. Additionally, information should be provided on the range of outcomes for individuals living with the diagnosed condition, including physical, developmental, educational and psychosocial outcomes. The law offers referrals to support services such as hotlines, websites, and informational clearinghouses. It calls for the creation of a network of adoption registries and the strengthening of parent support networks and programs for those who receive a prenatal or postnatal diagnosis of Down syndrome or other disorders.

The intent of the law is to create a sensitive, coherent and collaborative process for delivering information about the diagnosis across the variety of medical professionals — physicians, genetic counselors, geneticists, nurses, midwives and technicians-- who currently deliver a diagnosis, to avoid any conflicting, inaccurate or incomplete information. Also, the legislation would promote the rapid establishments of links to community supports and services for parents who choose to take their baby with Down syndrome home or for those who choose to have their child adopted.

It is estimated that more than 1,000 prenatal tests are available or in development. Included among them are tests for conditions that are not life-threatening, could be helped by surgery or medical care, or don't appear until adulthood. The prognoses for people with some prenatally diagnosable disabilities have been improving markedly in recent years, leaving medical professionals scrambling to keep up with changing data and the need to communicate complex information to the over four million women who are now offered prenatal screening and testing and must weigh this information in order to give informed consent for these new procedures.

As reported in an article entitled "Changing Practice of Obstetricians", published in the American Journal of Obstetrics and Gynecology in April 2009, only 36% of obstetricians feel "well qualified to counsel patients who screen positive" for Down syndrome.... About half (51%) thought the training they received during residency regarding screening and diagnosis for Down syndrome was adequate, whereas 40% thought it was less than adequate and 9% thought it was comprehensive." When a fetus was diagnosed with Down syndrome only 29% of physicians provided the pregnant woman with printed educational materials.

Another study published in the American Journal of Medical Genetics yielded recommendations about how the diagnosis should be delivered. A 29-member research team studied the opinions of couples who had received the diagnosis to determine the best way of delivering the news and learned that mothers were emphatic that they wanted to discuss with physicians all options available to them, including continuing the pregnancy, placing the baby up for adoption

after birth, or pursuing termination<sup>1</sup>. Studies also indicate that couples want screening results clearly explained as a risk assessment, not as a “positive” or “negative” result; they preferred to discuss all reasons for prenatal diagnosis; they preferred that results from amniocentesis or CVS, chorionic villi sampling, should, whenever possible, be delivered in person, with both parents present, if possible, or by a pre-arranged call if an in-person meeting were not possible; they desired that sensitive language should be used when delivering a diagnosis of Down syndrome and that sensitive, accurate, and consistent messages be conveyed; and contact with local Down syndrome support groups should be offered, if desired.

By including \$5 million in the FY 2011 Labor, Health & Human Services, Education, and Related Agencies Appropriations Bill, the Department of Health and Human Services (HHS) will be able to fund its responsibilities to:

- Collect and distribute information relating to Down syndrome and other prenatally or postnatally diagnosed conditions;
- Coordinate the provision of supportive services for patients receiving a positive diagnosis of a prenatally or postnatally diagnosed condition; and
- Oversee the new requirements for health care providers established by the law. The funding is also needed to carry out the requirement that the CDC assist state and local health departments to integrate testing results into surveillance systems.

Mr. Chairman, thank you for your time and attention. Given the considerable impact this condition has on families and communities across the country, the promise of further assistance and improving research outcomes for individuals with Down syndrome is crucial. We are thrilled beyond measure that Congress enacted this legislation and hope that funding this request will help to shift the way the nation regards individuals with disabilities. Through providing accurate, updated information about diagnosable conditions like Down syndrome to pregnant women, the expectation is that individuals and families will make better, more informed decisions. But the bigger impact will be better understanding on the part of the American people about the nature of disability and the value of these citizens to their families, their communities and to our country. Should you have any questions or require additional information, please feel free to call on me.

1. Skotko, B., Kishnani, P., & Capone, G. for the Down Syndrome Diagnosis Study Group (2009). Prenatal diagnosis of Down syndrome: How best to deliver the news. *American Journal of Medical Genetics, Part A*, 149A: 2361-2367

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<sup>1</sup> Skotko, B., Kishnani, P., & Capone, G. for the Down Syndrome Diagnosis Study Group (2009). Prenatal diagnosis of Down syndrome: How best to deliver the news. *American Journal of Medical Genetics, Part A*, 149A: 2361-2367